

Dear Chair Durheim and the DD Council,

I'm writing to provide public comment on the activities of the Council. I would prefer to simply write you as a self-advocate within the state of Texas, but no matter what I write or when I compose this letter I am inextricably linked to Texas Advocates. I would still ask you to remember that I am part of the population this Council serves, whatever professional hats I may happen to wear.

Besides having administered two DD Council grants, I have also been a participant. In late 2011 I participated in a Leadership & Development in the Houston area. This was a great experience, and I met a lot of great people that I still interact with now.

However, there were some marked differences with that experience to experiences somewhere like Texas Advocates. I was one of only two self-advocates participating in a class of about thirty, and as far as I could tell, the only one with a cognitive disability. None of the employees were self-advocates, nor, as far as I knew, the volunteers. And most of the experts, again, were family members.

This had some impact on my experience. It was a difficult learning experience at times being the only self-advocate in the room, with parents who were unlearning a sometimes hostile worldview, despite the best efforts of the grantee to facilitate that process. The course was also very much designed for family members with the welcome participation of self-advocates, rather than being designed with self-advocates in mind: for example, each class took place on the 2<sup>nd</sup> Saturday of the month, except the last class, in December, which took place on the 1<sup>st</sup> Saturday. I scheduled my trips around this timing like clockwork, and missed the last training—luckily someone called to tell me or I would have ended up stranded in Sugar Land for 8 hours on that last day!

I want you to understand that none of this is a complaint about the grantor, whom I adore, recommend, and would fund were it in my power. I'm telling this to illustrate the difference in an environment designed for non-disabled family members, even one that makes efforts to include self-advocates, and one designed for people with DD. On the SAVE grant, which I completed this year, all of the participants had an I/DD, as did their project coordinator, and so there was no expectation that participants would remember a schedule. They were contacted ahead of a class, sometimes multiple times, to remind them of the time and date. The length of the training was modified to fit the group's attention span, and breaks were added to facilitate learning. The frequency of classes increased to better retention. Topics changed or were introduced in different ways to better facilitate learning—and if I could do it over again, I'd probably change some more.

Parent groups serve an important function, but so do self-advocate groups, which are less-funded, less independent, less prioritized when they are supported by another organization, and less prestigious. That's why I would like you to consider and implement a separate funding source for self-advocate groups, especially as you are developing your next 5-Year Plan. I would like to see an entire category of grants, like Leadership & Development grants, specifically dedicated to funding self-advocate groups. The Council would know better what level of grants most self-advocate groups could apply for, but this way a single grant like the Community Organizing grant, dedicated specifically to self-advocate groups, doesn't get swallowed up by Texas Advocates, and smaller self-advocate groups have a chance to acquire these funds too.

Thank you for your consideration of this matter,

Shaun Bickley